AD			

Award Number: W81XWH-12-1-0589

TITLE: Cognitions, Decisions, and Behaviors Related to Successful Adjustment among Individuals with SCI: A Qualitative Examination of Military and Nonmilitary Personnel

PRINCIPAL INVESTIGATOR: Michelle A. Meade, PhD.

CONTRACTING ORGANIZATION: Regents of the University of Michigan Ann Arbor, MI 48109

REPORT DATE: October 2015

TYPE OF REPORT: Annual Report

PREPARED FOR: U.S. Army Medical Research and Materiel Command Fort Detrick, Maryland 21702-5012

DISTRIBUTION STATEMENT: Approved for Public Release; Distribution Unlimited

The views, opinions and/or findings contained in this report are those of the author(s) and should not be construed as an official Department of the Army position, policy or decision unless so designated by other documentation.

REPORT DOCUMENTATION PAGE

Form Approved

OMB No. 0704-0188

Public reporting burden for this collection of information is estimated to average 1 hour per response, including the time for reviewing instructions, searching existing data sources, gathering and maintaining the data needed, and completing and reviewing this collection of information. Send comments regarding this burden estimate or any other aspect of this collection of information, including suggestions for reducing this burden to Department of Defense, Washington Headquarters Services, Directorate for Information Operations and Reports (0704-0188), 1215 Jefferson Davis Highway, Suite 1204, Arlington, VA 22202-4302. Respondents should be aware that notwithstanding any other provision of law, no person shall be subject to any penalty for failing to comply with a collection of information if it does not display a currently valid OMB control number. PLEASE DO NOT RETURN YOUR FORM TO

1. REPORT DATE	2. REPORT TYPE	3. DATES COVERED
October 2015	Annual	30 Sep 2014 - 29 Sep 2015
A. TITLE AND SUBTITLE		5a. CONTRACT NUMBER
Cognitions, Decisions and Behavi	iors Related to Successful Adjustment Among individu	uals 5b. GRANT NUMBER
with SCI: A Qualitative Examinat	tion of Military and Nonmilitary Personnel	W81XWH-12-1-0589
		5c. PROGRAM ELEMENT NUMBER
6. AUTHOR(S)		5d. PROJECT NUMBER
Michelle A. Meade and Bradle	ey L. Trumpower	5e. TASK NUMBER
E-Mail: trumpb@med.umich	.edu	5f. WORK UNIT NUMBER
7. PERFORMING ORGANIZATION	NAME(S) AND ADDRESS(ES)	8. PERFORMING ORGANIZATION REPORT NUMBER
The Regents of the University	of Michigan.	
3003 South State Street		
Ann Arbor, MI 48109-1272.		
9. SPONSORING / MONITORING ACU.S. Army Medical Research and	GENCY NAME(S) AND ADDRESS(ES) I Materiel Command	10. SPONSOR/MONITOR'S ACRONYM(S)
Fort Detrick, Maryland 21702-50		
•		11. SPONSOR/MONITOR'S REPORT NUMBER(S)

Approved for Public Release; Distribution Unlimited

13. SUPPLEMENTARY NOTES

14. ABSTRACT

This project is designed to find out how successful adjustment happens after SCI. Successful individuals will be identified from four sites through a mail survey. Those individuals (both those from military backgrounds and others) are being recruited to take part in an in-depth qualitative interview to help identify key factors in successful adjustment after SCI. The project has received 475 eligible responses to the survey from the 4 recruitment sites and we have begun to analyze and present on the data. The qualitative phase of the study was well underway. By the end of year 3, we had completed 41 (of the 60 planned) interviews and are beginning to examine and present on trends related to cognitive and psychosocial characteristics among individuals who have been identified as having successfully adjusted to SCI.

15. SUBJECT TERMS

Spinal cord injury, resilience, adjustment, qualitative research

16. SECURITY CLASS	SIFICATION OF:		17. LIMITATION OF ABSTRACT	18. NUMBER OF PAGES	19a. NAME OF RESPONSIBLE PERSON US AMRMC
a. REPORT U	b. ABSTRACT U	c. THIS PAGE U	UU	76	19b. TELEPHONE NUMBER (include area code)

Table of Contents

Introduction	4
Body	
Key Research Accomplishments	
Reportable Outcomes	
References	
Appendix A	18
Appendix B	
Appendix C	

Introduction

This project is designed to find out how successful adjustment happens after SCI. We have started by identifying "successful" and resilient individuals with SCI via a mail survey to the known population of individuals with SCI served by the associated project sites (phase 1). We then recruited a stratified sample of successful individuals and used qualitative techniques to gather details from them about their lives and experiences (phase 2). We are focused these qualitative interviews on finding out about the thoughts they had, the decisions they made and the behaviors they performed in the first few years after injury, as well as what factors influenced these. By illuminating the process of positive adjustment and successful self-regulation after SCI and articulating specific and concrete cognitions, decisions and behaviors, this project will provide foundational information to enhance existing interventions and develop new assessments and programs.

Body

We are pleased with the project that we have made on the project. While the project encountered significant delays in obtaining all of the necessary approvals from the various Human Subjects Review Boards and the Department of Defense. At this, the third year annual report, we have completed phase 1 of the projects and most of the individuals interviews (Phase 2). We have worked to maintain contact with the various project and contract officers and to conduct dissemination and knowledge translation activities. In this last year of the project – now in a not cost extension – we will continue to disseminate the findings from phase 1 and complete the individual interviews and analyze and disseminate the data from them. Most importantly, though, we will continue to conduct knowledge translation activities.

Regulatory Review and Approval Process

This project involves two phases (mail survey and qualitative interviews) which have been submitted as two separate studies to the University of Michigan IRB. In addition, the mail survey (phase one) study has been submitted to the IRB at the Rehabilitation Institute of Michigan and the Ann Arbor VA and approved. While the DoD considers the Paralyzed Veterans of Michigan (PVA) as its own site, it does not have an IRB and so is included under the University of Michigan IRB. As approvals have been received from a site, the approvals have been submitted to the DOD. The second phase was the qualitative interviews. This was approved to be conducted at the University of Michigan. All sites are approved or closed (RIM) as appropriate.

Phase One: Screening Survey

The survey process has been completed for all sites of the study. We mailed surveys to 1912 individuals with Spinal Cord Injury, at least 152 of which were returned because of bad addresses or ineligibility. We received completed surveys from 642 individuals. We later determined that there were surveys received from individuals who were not eligible. One of our partner organizations sent the survey to all members of their organization. Unfortunately, this included individuals with other causes of paralysis than traumatic spinal cord injury. In addition, we found that some of the individuals recruited from the University of Michigan had a mention of a SCI in their medical records but were later determined not to have a traumatic SCI. To obtain a more accurate count, we reviewed the medical records of all participants from the University of Michigan. Of those 642 individuals, we found that 475 were eligible. This gives us a response rate of 29.8%.

Because we did not have access to this list and their diagnoses, we implemented a stronger screening process for Phase Two. We also determined that some individuals recruited from the University of Michigan may have had an initial diagnosis of SCI but were later determined to not have SCI. To remove these individuals, we reviewed the medical records of all participants from the University of Michigan. This procedure revealed that 159 of the original survey respondents and 55 of the 169 individuals who were thought to be eligible for phase two of this study had to be excluded because of misinformation about their eligibility.

Table 1. Demographic Characteristics of Survey Respondents

Characteristic	n	% or Mean ± SD (range)
Age	470	53.81 ± 15.20 (19-93)
Time since injury	460	$17.93 \pm 14.68 \ (0.25-75)$
Time since injury	400	17.73 ± 14.00 (0.23 73)
Gender		
Male	375	79.11%
Female	91	19.2%
Missing	8	1.69%
Level of Injury		
Bet ween C1 and C4	82	17.3%
Requires Ventilator	7	8.54% (of C1-C4)
Between C5 and C8	124	26.16%
Between T1 and T12	153	32.28%
Between L1 and S3	42	8.86%
Don't know/not sure	50	10.55%
Missing	23	4.85%
Movement below level of injury		
Yes	277	58.44%
No	181	38.19%
Missing	16	3.38%
Feeling below level of injury		
Yes	301	63.5%
No	147	31.01%
Missing	26	5.49%
Race		
White	385	81.22%
Black	42	8.86%
Multiracial	19	4.01%
Other	18	3.8%
Missing	10	2.11%
		. = = /*
Education Level		<u> </u>
Not graduated from high school	27	5.7%
Completed high school / GED	109	23%
Some college or more	330	69.62%
Missing	8	1.69%

61	12.87%	
172	36.29%	
221	46.62%	
20	4.22%	
	172 221	172 36.29% 221 46.62%

Employed			
Yes	107	22.57%	
No	356	75.11%	
Missing	11	2.32%	

Household Income			
Less than \$20,000	104	21.94%	
\$20,000 to \$29,999	54	11.39%	
\$30,000 to \$39,999	46	9.70%	
\$40,000 to 59,999	73	15.40%	
\$60,000 to \$79,999	44	9.28%	
\$80,000 and over	95	20.04%	
Missing	58	12.24%	

Marital Status		
Single	125	26.37%
Married/Partnered	231	48.73%
Separated/Divorced	90	18.99%
Widowed	20	4.22%
Missing	8	1.69%

Military Service			
Yes	224	47.26%	
No	244	51.48%	
Missing	6	1.27%	

Note: Total n of respondents=475

Table 2. Sub-characteristics of Military Sample (n=224)

Characteristic		Yes		No	Mi	issing
	n	%	n	%	n	%
Participated in Combat	70	14.77%	148	31.22%	256	54.01%
Receives VA Benefits	156	32.91%	64	13.5%	254	53.59%
Receive Care at VA health facility	167	35.23%	55	11.6%	252	53.16%
Service Connected SCI	86	18.14%	133	28.06%	255	53.8%

This is the first study that we know of that has used the Flourishing scale with individuals with SCI. As responses to the Satisfaction with Life Scale (SWLS) were also collected, this data will be useful in supporting a more positive focus on life after SCI. This will be one of the manuscripts scheduled to be written this year and submitted to a peer reviewed journal.

Table 3. Satisfaction with Life Scale (SWLS) Comparisons¹

Sample	n	Mean ± SD
normative sample	129	21.0 ± 7.7
survey sample	458	18.85 ± 8.11
interviewed sample	59	23.17 ± 7.75

Table 4. Flourishing Scale Comparisons²

Sample	n	Mean ±SD
normative sample	689	44.97 ± 0.87
survey sample	454	41.61 ± 10.21
interviewed sample	60	49.55 3.59

Almost half of survey respondents (n=231;48.6%) took the time to add write-in comments to the question "Is there anything else about resilience that you wanted to tell us?" This level of response suggests that the survey questions resonated with those who bothered to complete them, such that they took the extra time needed to consider and write about their perspective as opposed to just checking a box. We have analyzed these responses and categorized them as reflecting 8 areas – Resilience, General Outlook on Life, Social support and social relationships, Physical Health and Functioning (Including pain), Religion or Faith in a Higher Power, Mood, Comparisons and Resources. These responses are available in Appendix F and the paper detailing this analysis has been accepted for publication in Topics of SCI Rehabilitation due out in Spring of 2016.

Phase Two - Qualitative Interviews

Stratification

We identified potential participants for the in-depth interviews from the pool of individuals who completed the screening survey based on their responses; we attempted to recruit at least five individuals from each stratification group, for a total of 60 participants. We used three factors to stratify individuals. These factors were military veteran status, resource level, and years since injury.

We split up resources by using the survey responses for household income, auto insurance, and service connection for SCI. In Michigan, if the trauma that results in SCI is related to an automobile, these individuals have increased assistance from their auto insurance company. Years since injury was split into two groups: 2-10 years and 10 or more years since their injury.

Table 5. Resource Level Determination

Household Income	Auto Insurance or Service Connection	Resource Level
<\$29,999	no	low
	yes	medium
\$30K-\$59,999	no	medium
	yes	high
\$60K+	no	high
	yes	high

We used the Flourishing Scale to determine eligibility for the interviews. Initially, the limit for eligibility was set at 48 or higher. We later had to adjust this limit for some stratification categories in an attempt to fill those categories. This has resulted in the following breakdown of participants in each stratification category:

Table 6. Interview Stratification

iusie v. intel view strutification							
Group	Resource Level		2-10	10+			
		Eligible	Completed	Eligible	Completed		
Military (n=29)		13	5	39	24		
	Low	7	1	11	7		
	Medium	4	2	9	5		
	High	2	2	19	12		
Non-military (n=31)		25	16	35	15		
	Low	9	6	9	4		
	Medium	7	5	13	5		
	High	9	5	13	6		



Figure 1: Map of Phase Two Participants

As of September 30th, 2015, we completed 41 of 60 interviews. In January 2016, all 60 interviews were completed. Figure 1 shows a map of the locations of each interviewee; Table 7 includes the breakdown of the characteristics of those interviewed.

Table 7: Interview Subjects Characteristics

Characteristic	n	(%) or Mean ± SD (range)
Age	60	$50.58 \pm 15.80 \ (19-89)$
Years post injury	60	$16.49 \pm 12.19 (1-47)$
Gender		
Male	51	85%
Female	9	15%
Level of Injury		
Between C1 and C4	10	16.67%
Bet ween C5 and C8	16	26.67%
Between T1 and T12	25	41.67%
Between L1 and S3	7	11.67%
Don't know/not sure	2	3.33%

Movement below level of injury		
Yes	31	51.67%
No	29	48.33%
110	2)	70.5570
Feeling belowlevel of injury		
Yes	37	61.67%
No	23	38.33%
Race		
White	51	85.00%
Black	4	6.67%
Native Hawaiian or Other Pacific Islander	1	1.67%
multiracial	4	6.67%
marmaciai		0.0770
Education Level		
High school/GED	13	21.67%
Some college / Associates degree	23	38.33%
Bachelors degree	14	23.33%
Graduate study or degree	10	16.67%
Location Description		
Urban	8	13.33%
Suburban	22	36.67%
Small town / rural	28	46.67%
Missing	2	3.33%
Employed		
Yes	19	31.67%
No	40	66.67%
Missing	1	1.67%
Missing	1	1.07 /0
Household Income		
Less than \$20,000	12	20%
\$20,000 to \$29,999	7	11.67%
\$30,000 to \$39,999	9	15%
\$40,000 to 59,999	10	16.67%
\$60,000 to \$79,999	3	5%
\$80,000 and over	18	30%
Marital Status		
Single	18	30%
Married/ Partnered	27	45%
Divorced	12	20%
Widowed	2	3.33%
Missing	1	1.67%

Military Camina		
Military Service	20	40.220/
Yes	29	48.33%
No	31	51.67%
Participated in Combat (n=29)		
Yes	10	34.48%
No	18	62.07%
Missing	1	3.45%
Receive VA Benefits (n=29)		
Yes	19	65.52%
No	10	34.48%
Receive Care at VA Health Facility (n=29)		
Yes	22	75.86%
No	7	24.14%
Service-connected for SCI (n=29)		
Yes	9	31.03%
No	20	69.97%

Table 8. Sub-characteristics of Interviewed Military Sample (n=29)

Characteristic	n (%)				
	Yes	No	Missing		
Participated in Combat	10 (34.48%)	18 (62.07%)	1 (3.45%)		
Receive VA Benefits	19 (65.52%)	10 (34.48%)			
Receive Care at VA Health Facility	22 (75.86%)	7 (24.14%)			
Service-connected for SCI	9 (31.03%)	20 (69.97%)			

The Next Year

The steps to be completed in the next year include continuing review of the transcripts. This is done to ensure accuracy and completeness of the qualitative data. These "cleaned" transcripts are then uploaded into NVIVO, a qualitative software, to facilitate the processing and analysis. An index and coding scheme is being developed based on theoretical concepts embedded in the research questions and precise and standard definitions and examples to ensure that individual coders consistently apply the codes to the narrative text. This coding scheme will be updated and modified as needed during the analysis. All procedures and rationale for coding will be recorded to support consistency, dependability, and duplicability of results.

After the transcripts have been coded, they will be analyzed to identify specific cognitions, decisions, and behaviors that were cited as key in resilience. The results from this analysis will be shared with the interview participants and other interested parties in a feedback session. The goal of this session is to disseminate the information and to continue to include the SCI community in developing strategies to improve outcomes. We will review our analyses in light of information gained from this feedback session. We will use this analysis to develop further presentations and manuscripts for publication.

Key Research Accomplishments

While we are in the process of analyzing responses to both quantitative and qualitative responses to the survey and in-depth interviews, initial findings suggest:

Success after SCI, as operationalized by higher scores on the Flourishing scale, is negatively correlated with current age (r=-.152) and number of secondary conditions (r=-.333) and positively correlated with household Income (rho=.212), and education: (rho=.200). Examination of flourishing scores between groups reveals that veterans, those who are not employed, and those who see themselves as worse off when compared to others have lower scores. Time since injury, gender and level of SCI do not appear related to outcomes on the Flourishing scale.

Table 9. Flourishing Scale Correlations

		No. of Secondary Conditions	Age	Household Income	Level of Education
Flourishing Scale Total	Pearson Correlation	333**	152**	.212**	.200**
	Sig. (2-tailed)	.000	.001	.000	.000
	N	454	451	400	446

^{**.} Correlation is significant at the 0.01 level (2-tailed).

Table 10. Flourishing Scale - Notable Insignificant Correlations

		Time Since Injury	Level of SCI	Gender
Flourishing Scale Total	Pearson Correlation	.030	069	.074
	Sig. (2-tailed)	.534 443	.153 435	.117 446

^{**.} Correlation is significant at the 0.01 level (2-tailed).

Table 11. Flourishing Scale and Veteran Status

M	ilitary Veteran	N	Mean ± SD (range)
Yes	Flourishing Scale Total	212	40.10 ± 11.02 (8-56)
No	Flourishing Scale Total	236	43.14 ± 9.16 (5-56)

Table 12. Flourishing Scale and differences in Health Comparison

Health C	omparison	N	Minimum	Maximum	Mean	Std. Deviation
Better off	Flourishing Scale Total	92	8.00	56.00	47.5543	9.56914
Worse off	Flourishing Scale Total	156	9.00	50.00	35.3397	9.79236
About the same	Flourishing Scale Total	193	22.00	56.00	43.9845	7.60241

Table 13. Flourishing Scale and Employment

Em plo	oyment s	N	Minimum	Maximum	Mean	Std. Deviation
Yes	Flourishing Scale Total	105	8.00	56.00	46.6571	9.01370
No	Flourishing Scale Total	339	8.00	56.00	39.9086	10.12995

When a Univariates Generalized linear model (GLM) was used to determine significant predictors for flourishing, paid employment and the general rating of health were found to be significant. However, the importance of current employment lessened in significance when social comparisons were added to the model.

Table 14. Tests of Between-Subjects Effects: Model without Social Comparisons

Source	Type IV Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power ^b
Corrected Model	8817.004 ^a	16	551.063	7.753	.000	.286	124.048	1.000
Intercept	7310.391	1	7310.391	102.851	.000	.249	102.851	1.000
Level of injury	361.879	3	120.626	1.697	.168	.016	5.091	.443
Feeling below injury	41.911	1	41.911	.590	.443	.002	.590	.119
Movement belowinjury	103.616	1	103.616	1.458	.228	.005	1.458	.226
Paid employment	296.107	1	296.107	4.166	.042	.013	4.166	.530
Military service	7.897	1	7.897	.111	.739	.000	.111	.063
Educational category	75.122	3	25.041	.352	.788	.003	1.057	.119
Current age	4.531	1	4.531	.064	.801	.000	.064	.057
Years since injury	112.654	1	112.654	1.585	.209	.005	1.585	.241
# Secondary Cond	200.392	1	200.392	2.819	.094	.009	2.819	.388

Rating of general health	2547.780	1	2547.780	35.845	.000	.104	35.845	1.000
Household Income	87.310	2	43.655	.614	.542	.004	1.228	.152
Error	22033.919	310	71.077					
Total	626563.000	327						
Corrected Total	30850.924	326						

R Squared = .286 (Adjusted R Squared = .249); Computed using alpha = .05

Table 15. Tests of Between-Subjects Effects: With Variable asking about Social Comparisons

Source	Type IV Sum of Squares	df	Mean Square	F	Sig.	Partial Eta Squared	Noncent. Parameter	Observed Power ^b
Corrected Model	10669.362 ^a	17	627.610	9.785	.000	.351	166.341	1.000
Intercept	8153.444	1	8153.444	127.116	.000	.293	127.116	1.000
Level of SCI	238.746	3	79.582	1.241	.295	.012	3.722	.331
Move below SCI	54.401	1	54.401	.848	.358	.003	.848	.151
Paid Employ	137.106	1	137.106	2.138	.145	.007	2.138	.308
Military Service	31.453	1	31.453	.490	.484	.002	.490	.107
Educ Category	75.488	3	25.163	.392	.759	.004	1.177	.127
Current age	4.158	1	4.158	.065	.799	.000	.065	.057
Yrs since injury	100.732	1	100.732	1.570	.211	.005	1.570	.239
Num Sec Con	16.951	1	16.951	.264	.608	.001	.264	.081
Health rating	1051.727	1	1051.727	16.397	.000	.051	16.397	.981
HH Income	18.979	2	9.490	.148	.863	.001	.296	.073
Comparisons	2457.281	2	1228.641	19.155	.000	.111	38.310	1.000
Error	19691.481	307	64.142					
Total	622802.000	325						
Corrected Total	30360.843	324						

a. R Squared = .351 (Adjusted R Squared = .316); Computed using alpha = .05

The issue of resilience and ability to "bounce back from a challenge" appeared to resonate with individuals with SCI living in the community such that approximately half of survey participants took the time to respond to an open ended question about this. Qualitative analysis revealed 8 categories of responses which provided insight into self-reported facilitators and barriers associated with adjustment and happiness following SCI. Eight categories were identified: resilience, general outlook on life, social support and social relationships, religion or faith in a higher power, physical health and functioning, mood, comparisons, and resources. These categories encompassed 18 overlapping themes that increased understanding of the factors that are related to resilience among adults with SCI living in the community. Consistent with previous research the majority of

respondents described themselves as being happy "all or most of the time." Overall, the categories and themes articulated appear to be consistent with the research supporting the use of the Stress Appraisal and Coping Model to understand adjustment following SCI. In particular, our findings highlight the frequency that individuals with SCI perceive themselves as being happy how this appears to be connected with self-identification as being resilient, employing strategies to reframe one's experience, and having a sense of support from friends or a higher power. A primary limitation of this analysis, though, is self-selection bias; that is, only individuals who decided to complete the open-ended question and participate in the larger survey were included. Although the sample remains fairly large and diverse for a qualitative study, it is undoubtedly weighted to reflect the perspectives of individuals with SCI who had the energy and motivation to participate.

Early analysis on data from the a limited number of individuals who participated in the qualitative interviews (n=10) suggested that individuals with SCI whose scores on the Flourishing scale suggest that they feel that their life has meaning appear to more likely score on the average range or above (on the NEO) for extraversion and at the below average level for Neuroticism.

Rourishing Scale Pearson Correlation Sig. (2-tailed) N 60

Table 16. Flourishing Scale and Neuroticism Correlations

However, when available data from all phase 2 participants who were able to complete the Stroop (n=52) was analyzed, different relationships emerged. In particular, only a limited number of factors were found to be related to Cognitive Flexibility (and Attention) as measured by Stroop Tasks.

- Better performance related to Attention (as measured by S-C) was seen among individuals with SCI at the higher income level, suggesting a need to further explore the relationship between executive functioning and the variety of factors contributing to SES among individuals with long-standing SCI
- Cognitive flexibility (as measured by S-CW) was related to marital status such that participants who were single showed more cognitive flexibility while those who were or had been married / partnered showed less
- Cognitive flexibility was also associated with age, with younger participants showing greater flexibility; this finding is consistent with the general population
- The lack of findings and limited variability on the measure of cognitive flexibility suggests that a baseline level of attention and cognitive flexibility may be required by those with SCI who are able to adapt successfully
- While this sample of individuals with SCI identified as Flourishing appears to be similar to the general
 population as related to attention and cognitive flexibility (as measures by the Stroop), the personality
 profiles suggests distinct differences as all of the NEO scales were significantly higher than the test
 norms.

^{*.} Correlation is significant at the 0.05 level (2-tailed).

• These scores suggest that this sample has more of all the personality characteristics – be it openness, extroversion, neuroticism, conscientiousness and agreeableness. Additional research is needed to further examine and explain this finding using a larger sample. The adaptive may indicate more positive characteristics (such openness).

These findings highlight the need to more research to determine what cognitive characteristics may translate to functionally more significant gains after SCI.

Reportable Outcomes

There have been three presentations at national conferences, two at University of Michigan conferences and one manuscript accepted for publication. A copy of the manuscript is in Appendix B.

- Harman I, Trumpower B & Meade M (2015). Personality Factors Among Individuals with Spinal Cord Injury who are Flourishing. Undergraduate Research Opportunity Program (UROP) Poster Presentation, University of Michigan April 2015.
- Cadorin A, Trumpower B, Meade M, Duggan C & DiPonio L (2015). Flourishing and Resilience Among Individuals with Spinal Cord Injury. Poster presented at 32nd Annual James W. Rae Scientific Day, Department of Physical Medicine and Rehabilitation, University of Michigan, Ann Arbor, MI, May 15, 2015
- Trumpower B & Meade M (2015). Factors Associated with Flourishing & Successful Adjustment Among
- Individuals with Spinal Cord Injury (SCI). Research Presentation at the Academy of SCI Professionals, New Orleans, LA, September 2015.
- Meade, M & Wilson (2016). Resilience, Flourishing and Disability –Knowledge Translation with an Eye towards Innovation. Workshop presented at Rehabilitation Psychology 2016 Conference, Atlanta, GA, March 19, 2016.
- Sol, K. &V Meade, M (2016). Exploratory Study of Factors Contributing to Successful Adjustment Following SCI by Examining Cognitive Flexibility. Poster presented at Rehabilitation Psychology 2016 Conference, Atlanta, GA, March 20, 2016.
- Duggan C, Wilson C, DiPonio L, Trumpower B, & Meade, MA (in press). Resilience and Happiness After Spinal Cord Injury: A Qualitative Study. *Topics in Spinal Cord Rehabilitation*, Spring 2016.

Conclusion

There are a significant number of individuals living well with Spinal Cord Injury. While it is possible that respondents to our survey do not necessarily reflect the entire population, their responses assert that living a good life and flourishing after SCI is possible. We are looking forward to completing the analysis which will provide much more information both about individual cognitions, decisions and behaviors and how those related to current positive outcomes in addition to identifying the potential role of personality and cognitive flexibility in this process.

References

1. Post, M. W., Van Leeuwen, C. M., Van Koppenhagen, C. F., & De Groot, S. (2012). Validity of the Life Satisfaction Questions, the Life Satisfaction Questionnaire, and the Satisfaction With Life Scale in

Persons With Spinal Cord Injury. Archives of Physical Medicine and Rehabilitation, 93(10), 1832-1837. Retrieved February 17, 2016.

2. Diener, E., Wirtz, D., Tov, W., Kim-Prieto, C., Choi, D.-. won., Oishi, S., & Biswas-Diener, R.. (2010). New Well-being Measures: Short Scales to Assess Flourishing and Positive and Negative Feelings. Social Indicators Research, 97(2), 143–156. Retrieved from http://www.jstor.org/stable/40649361

Appendices

Appendix A: Survey on Adjustment and Quality of Life

Appendix B: Manuscript Accepted for Publication in Topics in Spinal Cord Rehabilitation, Spring 2016

Appendix C: Response Categories and Levels of Happiness

Appendix A: Survey on Adjustment and Quality of Life

Survey on Adjustment and Quality of Life



Great Lakes SCI Collaborative



DMCRehabilitation Institute of Michigan

always there.





THIS STUDY IS APPROVED BY THE ANN ARBOR DEPARTMENT OF VETERANS AFFAIRS HEALTHCARE SYSTEM

Section I: General Information about your Spinal Cord Injury (SCI)

1.	How old are you? years old
2.	How long have you had your spinal cord injury (SCI)? (in years)
3. [What is your highest level of SCI? Check one only: Between C1 and C4 Do you require a ventilator to breathe? Between C5 and C8 Between C5 and C8 Between L1 and S3 Don't know / not sure
4.	Do you have any feeling below your level of injury? \square^1 Yes \square^2 No
5.	Do you have any movement that is <u>under your control</u> below your level of injury?
	\square^1 Yes \square^2 No
6.	Section II: Health, Income and Access to Care Are you currently working at a job for which you receive pay?
a.	If yes, on average, how many <u>hours per week</u> do you work?
	Do you receive any of the following from your job? Check all that apply: 1 Health benefits 2 Paid vacation 3 Sick leave 4 Other:
	What is your household income (combined income for all members of your usehold) Check one only:
	Check one only: 1 Less than \$20,000 $4 $40,000 \text{ to } $59,999$ 2 \$20,000 to \$29,999 $5 $60,000 \text{ or } $79,999$ 3 \$30,000 to \$39,999 $6 $80,000 \text{ and over}$
L	

8. Do you cui	Yes ——		
Employer	health insuranc health plan health insurance	-	Check all that apply: Solution Check all that apply: Veterans Administration Auto Insurance Don't know / not sure Other:
9. In general,	would you say th	hat your health	is:
□¹ Poor	☐² Fair	\square^3 Good	☐ Very Good ☐ Excellent
10. Has there were not able t		ne last 12 month	s when you needed medical care but
1 Yes	l	\square^2 No	
Check one only Transperior Transperior Unable The control of t	<u>):</u>	th care provider	ly fashion
	experienced any		ng problems within the past 12 months
¹ Pressur	e sores / skin br		
	r problems, inclury accidents	uding frequent i	urinary tract infections (UTIs) or
Bowel Probler press	problems, incluns managing bloure and / or auto	ood pressure, inconomic dysrefle	enstipation or frequent bowel accidents cluding high blood pressure, low blood xia
	ent, chronic pain		depression or anxiety
	tory issues, inclu		
8 Sleep-r	,	dding phedinon	ıu
Other:	elated breathing	~ -	14

Section III: Quality of Life

12. Generally speaking, how would you describe yourself as being happy?									
\square^1 All the time	\square^2 Mos	t of the Ti	me _	Some o	of the tim	e			
☐ Very Infrequently	☐ Very Infrequently ☐ Not at All								
13. When you compare yourselves with other people you know, would you say you are:									
\square^1 Better Off \square^2 Worse Off \square^3 About the same									
14. Below are 8 statements with which you may agree or disagree. Using the 1 to 7 scale below, indicate your agreement with each item by checking the response for each statement.									
	Strongly disagree	Disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree		
I lead a purposeful and meaningful life.		2	3	4	5	6	7		
My social relationships are supportive and rewarding.		2	3	4	5	6	7		
I am engaged and interested in daily activities.		2	3	4	5	6	7		
I actively contribute to the happiness and well-being of others.	1		3	4	5	6	7		
I am competent and capable in the activities that are important to me.		2	3	4	5	6	7		
I am a good person and live a good life.	1	2	3	4	5	6	7		
I am optimistic about my future	1	2	3	4	5	6	7		
People respect me.	1	2	3	4	5	6	7		

15. Is there anything else "bounce back" when you f				-			-
16. Below are five states scale below, indicate your o your level of agreement.	agreemen	t with eac	ch item by	y checkin	g the box	that co	
	Strongly disagree	disagree	Slightly disagree	Neither agree nor disagree	Slightly agree	Agree	Strongly agree
a. In most ways my life is close to my ideal.	1	2	3	4	5	6	7
b. The conditions of my life are excellent.	1	2	3	4	5	6	7
c. I am satisfied with my life.	1	2	3	4	5	6	7
d. So far I have gotten the important things I want in life.		2	3	4	5	6	7
e. If I could live my life over, I would change almost nothing		2	3	4	5	6	7

Section IV: Demographic Information

17.	Gender:	\square^1 Male	\square^2 Female
18.	Marital Status: Single Divorced	☐ ² Married/Parti	nered 3 Separated
19.	Have you ever served in the mil		
	a. Did you participate in combat	:?	\square^1 Yes \square^2 No
	b. Do you receive Veterans Bene	efits?	\square^1 Yes \square^2 No
	c. Do you receive care at a Vete	rans Affairs Health Fa	cility? \square^1 Yes \square^2 No
	d. Are you service-connected for	r your SCI?	\square^1 Yes \square^2 No
20.	How would you describe the are		<u>eck one only:</u> Town / Rural
21.	What is your highest level of ed 1 Less than high school 2 Some high school 3 High school / GED Other:	Some college / AssoBachelor's degree	ociates degree
22.	What is your race / ethnicity? C	□ S Native Hawa In □ American Ind	niian / Other Pacific Islander dian, Alaska Native ntino
	If you checked more than one ca group best represents your race:	ategory, please indicate (write in race)	e which

UPON RETURN, THIS PAGE WILL BE SEPARATED AND STORED APART FROM THE REST OF YOUR SURVEY RESPONSES

23. If eligible, would you be willing to participate in an in-depth interview that will

•	-	you went through after your SCI? This lace at a location that would be					
□¹ Yes	\square^2 No	\square^3 Maybe – tell me more					
If you answered <u>yes</u> or <u>maybe</u> , please provide your name and a contact number or email. This information will be recorded by researchers at the University of Michigan who may use it to contact you for the in-depth interview. Your contact information would only be used to contact you for this follow-up interview, which is identified as a separate study, and not used for any other purpose.							
Name:							
Phone number or e-mail:							

Thank you for completing this survey

Please return it in the envelope provided

Appendix B: Manuscript Acc	epted for Publication in	Topics in Spinal Cord	Rehabilitation, Spring 2016

Resilience and Happiness after Spinal Cord Injury: A Qualitative Study

Abstract

The purpose of this study was to identify factors associated with resilience among individuals with spinal cord injury (SCI). Qualitative analyses were conducted of the written comments completed as part of a cross-sectional survey of individuals with SCI living in the community. More than 1800 mail surveys were distributed to individuals identified as having a traumatic SCI through the records and/or membership lists of 4 organizations. 475 individuals completed and returned the survey, with approximately half (48.6%; n=231) of respondents answering the open-ended question "Is there anything else you would like to tell us about your resilience or ability to 'bounce back' when you face a challenge?" Analyses of these responses identified both specific resources and cognitive perspectives that are associated with perceived happiness. Specifically, responses fell within eight general categories: Resilience, General Outlook on Life, Social Support and Social Relationships, Religion or Faith in a Higher Power, Mood, Physical Health and Functioning (including pain), Social Comparisons, and Resources. Nuanced themes within these categories were identified and generally concordant with selfreported level of happiness. Results showed that a majority of respondents with SCI identified themselves as happy and explained their adjustment and resilience as related to personality, good social support, and a spiritual connection. In contrast, pain and physical challenges appeared to be associated with limited ability to bounce back.

Resilience and Happiness after Spinal Cord Injury: A Qualitative Study

Colette Duggan¹

Catherine Wilson²

Lisa DiPonio³

Brad Trumpower³

Michelle A. Meade³

¹Rehabilitation Institute of Michigan, Detroit, Michigan, USA

²James A. Haley Veterans Hospital, Tampa, Florida, and Department of Physical Medicine and

Rehabilitation, Northwestern University Feinberg School of Medicine, Chicago, Illinois, USA

³ Department of Physical Medicine & Rehabilitation, University of Michigan School of

Medicine, Ann Arbor, Michigan, USA

Corresponding Author:

Michelle A. Meade, Ph.D.

Rehabilitation Psychology and Neuropsychology

University of Michigan Department of Physical Medicine & Rehabilitation

325 E. Eisenhower Pkwy

Ann Arbor, MI 48108-5744

Phone: 734-936-7052; fax: 734-936-7048

Email: mameade@umich.edu

Acknowledgments

Funding was provided through the proposal "Cognitions, Decisions, and Behaviors Related to Successful Adjustment Among Individuals With SCI: A Qualitative Examination of Military and Nonmilitary Personnel," funded through the Department of Defense, Proposal Log Number SC110130, Award Number W81XWH-12-1-0589, HRPO Log Number A-17615.1a

Support for use of REDCap was provided through the Michigan Institute for Clinical & Health Research grant support (CTSA: UL1TR000433).

Joanna Jennie assisted in the preparation of the manuscript.

Resilience and Happiness after Spinal Cord Injury: A Qualitative Study

Introduction

Adjustment to spinal cord injury (SCI) has been linked to important outcomes, including morbidity, mortality, healthcare costs, quality of life, and community reintegration. ^{1,2} Difficulties adapting to life with SCI correlate with high levels of emotional distress, substance abuse, and secondary conditions; self-reports of low quality of life; and increased risk for suicide. ³⁻⁵ In contrast, positive adjustment is associated with being able to continue with meaningful activities and goals to achieve positive outcomes. ¹

From the clinician's perspective, adjustment is often equated with the readiness, including motivation and skill, to perform needed behaviors to optimize rehabilitation and functional outcomes. Adjustment is seen as a dynamic and fluid process that interacts with intrapersonal, environmental, and biological factors to influence physical and psychological health and quality of life.^{2,6} Increasingly, research into adjustment includes a discussion of resilience. Resilience is defined as "the process of adapting well in the face of adversity, trauma, tragedy, threats or significant sources of stress.... [It] is not a trait that people either have or do not have. It involves behaviors, thoughts, and actions that anyone can learn and develop."⁷

However, despite the centricity of the concepts of adjustment and resilience to rehabilitation and community reintegration, the actual adjustment and self-regulatory processes that occur after SCI remain unclear.⁶ Only in the past few years has real attention been given to how cognitive appraisals and coping mediate adjustment to SCI.⁸⁻¹⁰ In addition, researchers have begun to translate concepts from the field of positive psychology and to examine the importance of a fighting spirit, finding meaning, and hope in mediating the relationship between functional status and psychological well-being.^{8,10-12}

This report describes selected findings from a cross-sectional survey of individuals in the community living with SCI. The survey was conducted as part of a larger project on successful adjustment following SCI. The objective of this study is to describe, from the perspective of individuals living with SCI, factors that they felt contributed to their resilience or "ability to bounce back" when they meet a challenge.

Methods

Survey development. As part of a larger multi-method and multi-site study, a 23-item survey (online Appendix A) was developed to identify adults with SCI living in the community who saw themselves as doing well and living meaningful lives. Survey questions were developed by study investigators in collaboration with an advisory council consisting of individuals with SCI, representatives from stakeholder organizations, and healthcare providers. Items pertained to personal factors, current health, and access to care, as well as questions about resilience and happiness. Injury-related characteristics were obtained by asking respondents closed-ended questions such as level of injury, number of years living with the injury, and feeling and movement below the level of injury. Embedded within the aforementioned survey were standardized scales of satisfaction with life and flourishing, 13-14 as well as questions specific to happiness and resilience. Specifically, participants were asked, "Generally speaking, would you describe yourself as being happy?" and responded on a five-point scale from "all the time" to "not at all." This question has been previously used as a brief assessment of subjective wellbeing in other studies. ¹⁵ Finally, participants had the opportunity to respond to the open-ended question: "Is there anything else you would like to tell us about your resilience or ability to 'bounce back' when you face a challenge?"

Recruitment of subjects

Study protocols were reviewed and human subject protection approvals obtained by the funding organization and relevant Institutional Review Boards. Survey participants were identified through medical records, membership lists, and SCI-related databases of the 4 organizations that collaborated on this project. This approach allowed researchers the opportunity to reach a broad spectrum of the known population of persons with traumatic SCI in southeastern Michigan and northern Ohio.

A cross-sectional mail survey design with a four-step approach was used. The four steps included sending participants: (a) a pre-notification post-card; (b) a packet which included a cover letter, the survey, a return envelope, and a small (\$3) incentive; (c) a reminder postcard; and (d) a second survey packet without incentive. More than 1800 mail surveys were distributed.

Data analyses

A three-step approach to content analysis was used to uncover and interpret the responses of study participants. The first step was to examine the actual words participants used to answer the survey question and to use those to articulate categories. Words that occur with great frequency are key to understanding survey respondents' understanding of resilience. It is essentially a quantitative technique that provides numeric counts, and thus has a certain degree of precision. 16-17

The second step to data analysis used a qualitative approach. For each of the categories identified, one of the authors (Duggan) examined the content of the replies provided by survey participants—their thoughts, feelings, or actions in relation to their life as a person living with SCI. Here the emphasis was not on frequency counts, but rather delineating meaningful themes (central ideas) associated with the responses of survey participants. Responses were reviewed

and themes were discussed with two of the other authors (Trumpower & Meade) before being finalized

Finally, after categories were identified and themes articulated, the authors examined and grouped responses within each theme by the respondent's self-described level of happiness (happy "all" or "most" of the time, "some" of the time, or "very infrequently" or "not at all").

Results

Demographic information and responses from the 231 individuals who answered the open-ended question "Is there anything else we should know about your resilience or ability to 'bounce back' after a challenge?" were extracted for analysis from the larger project database of 475 valid surveys. Characteristics of the sample used for this study are provided in Table 1.

[Table 1 about here]

Table 2 depicts the distribution of responses to the open-ended question by level of perceived happiness. Of the 231 individuals whose data were extracted for this study, more than half (58.4%) reported being happy all or most of the time.

[Table 2 about here]

The content analysis of the responses provided by survey participants uncovered eight distinct words or phrases directly or indirectly related to the ability to "bounce back" after SCI. Some respondents provided brief answers—a word, phrase, or single sentence. Others provided longer, more detailed responses incorporating more than one idea or theme. A total of 341 statements were identified. The qualitative analyses and articulation of the themes based on these categories are below; however, Table 3 shows the relationship between the frequency of responses in each category and the level of happiness. In particular, it is notable that all of the individuals who wrote about spirituality and religion and social comparisons reported being

happy at least some of the time. Online Appendix B provides a list of all of the responses, grouped according to category and identified by level of happiness.

[Table 3 about here]

Resilience

The most frequent category of responses (N=99) included words associated with resilience or similar constructs. Within this category, there were distinct themes of responses that mentioned (a) resilience as a skill or trait that individuals identified as having (or not), (b) facilitators of or barriers to resilience, and (c) specific activities and strategies—particularly cognitive restructuring—to support or achieve resilience.

The most common theme in this category was resilience as a trait. Within this theme, individuals stated:

...Challenges with everyday life don't tend to stop me and I bounce back fine.

Facing adversity and bouncing back is something I have done most of my life.

Mentally I am very strong and have been able to make the best out of bad situations my entire life.

At the opposite end of the continuum were individuals who spoke of a lack of resilience.

I no longer face problems/challenges 'head on.' Instead I hide hoping these things will blow over or just go away.

The second theme within this category pertained to facilitators of and barriers to resilience. Respondents also mentioned a variety of factors that either facilitated or impeded their ability to "bounce back" after SCI. Supportive factors included persistence, personal growth, a history of experiencing and facing adversity, and the ability to adapt to new situations. The following excerpt is representative of this aspect of the theme:

It is a constant battle, but after so many years you learn to bounce back quickly.

Barriers to resilience cited by respondents included the following: the sheer number of years living with SCI, the aging process, the accumulation of challenges over time, the number of challenges at any one point in time, a tendency to avoid problems, chronic pain, and the belief that no one could truly bounce back after a traumatic event. Individuals who took this approach typically described themselves as happy less often.

Wish I were younger and better physically to 'bounce back.' Wish I didn't tire so easily.

Chronic pain makes it hard to bounce back.

Finally, a number of respondents mentioned specific activities and strategies—particularly cognitive restructuring—to support or achieve resilience:

...I tell myself I'm the only one who has control of my life and can make it or break it, only me. I pull myself up by my bootstraps and move on.

I bounced back through adaptive sports and my education/career. Without them I would be miserable. My recovery was about getting back to my "normal" before injury.

I am good at compensating. If I can't do something, I looked for a new way to do it.

General outlook on life

The second most frequently mentioned category was general outlook on life (N=82), a concept that refers to a person's point of view, attitude toward life, or expectations for the future. Within this category, themes reflected (a) positive attitude or outlook, (b) a sense of personal responsibility, and (c) a mix of other types of approaches.

Responses which reflected the theme of positive attitude or outlook were particularly evident among participants who reported higher levels of happiness. What characterized their statements was a sense of optimism—the general belief that people can accomplish anything if

they put their mind to it. Also implied in their statements was a sense of purpose in life and the decision to focus more on the future and less on the past. Below are examples within this theme:

The past is behind you. Stop looking back and focus on the present (what you can do and accomplish).

Each day is a blessing—the good, bad and challenging we may face. Tomorrow is new day, a new page of life.

Purpose in life (and sheer force of will) can go a long way in overcoming major challenge.

Other survey respondents incorporated suggestions of actions or strategies they used to insure a positive outcome, such as seeking out "new ways of doing things," "working smarter, not harder," and "always push for improvement—stay well-read."

A second theme that could be seen within this category was a sense of personal responsibility. Statements appeared to reflect a sense of ownership to achieving independence or other outcomes of importance.

If you don't do it, nobody else will.

It's up to me, go backwards or forward. I'm not going backwards, have to stay positive, but it is hard. But I'm alive and my 3 girls need me. I have a whole bucket of problems, so I just put a lid on it.

In contrast, individuals who identified themselves as less happy were more likely to mention that their outlook on life had changed over the years, sometimes to the point of helplessness. These individuals often mentioned that they had been optimistic in the early years after injury, but at some point in time, the struggles they experienced were wearing them down.

I tried to be optimistic, but over the years of chronic pain, I have been worn down.

I've been known for my ability to see the good. So far I seem to be managing but just barely.

I still have moments of "Why me?"

Social support and social relationships

Social support and social relationships were frequently mentioned as part of the responses (N=49). The majority of respondents referred to persons in their immediate environment—including family members (spouse, children, and other relatives), friends, and other individuals who impacted their life (such as medical professionals and wheelchair sports teammates) as being crucial to their ability to bounce back in response to a challenge and specifically after their SCI.

Among those who mentioned the importance of social support, many identified personal qualities or attributes of the caregiver, such as constancy, consistency, love, and willingness to support their injured relative or friend in their recovery. The following comments are typical of this group of respondents.

Good family and friends support are a huge help.

My wife's support helps; the love of my family helps.

My husband was a "rock."

A significant number of respondents described the many ways that family and friends contributed to their ability to bounce back after SCI. Three themes appeared to be woven into these responses. The first subcategory acknowledged the importance of the tangible help of friends and family. Though specific activities were not mentioned, it was apparent from their brief answers that without assistance from family and friends, respondents would have had a

limited opportunity to participate in activities they had valued, enjoyed, and had always done in the past. The following comments illustrate this point:

I have my down days... but thank God I'm alive and have so many people who support me in things I want to do.

Good support from friends that won't keep the chair from letting you do things.

A more frequently mentioned benefit of social support was motivational. Social support was crucial in buffering respondents from the possible onset of future crises. Social support was also helpful in encouraging respondents to be engaged in day-to-day life, thus facilitating a sense of continuity in their lives post-SCI onset.

Without the support of my family and friends—would have "no drive to live" and little future. They make me strive to be better and to go a little further along life with a sure step.

I have two children that have kept me motivated not to give up.

Finally, survey participants identified the importance of reconnecting with their past life. Resuming former roles and responsibilities in the household and community provided a sense of purpose in life as well as productivity. It also provided a sense of continuity with their lives prior to injury.

Even though the deck is stacked against me, I have to keep getting up and moving forward because other people still depend on me.

I look at every day as another opportunity to be the best person I can for myself. And, more importantly, for the people around me.

Religion or faith in a higher power

Responses were notable for their inclusion of statements about religion or faith as a way of understanding and coping with the consequences of SCI (N=36). Some responses were brief, such as "faith" (or belief in a higher power), "prayer," or "amazing grace." Others provided responses that were more detailed and provided insight into the functions of religion and faith in their lives.

Below is a sampling of respondents' statements. Three themes appear to be embedded in the comments reflecting the various functions of religion in their lives: (1) support in the time of distress, (2) meaning and purpose in one's life and (future life) after death, and (3) praise and thanksgiving.

A significant religious theme embedded in the statements of survey respondents was their dependence and trust in "God" and support they received from "God" in time of stress. The following statements are reflective of this theme.

God give[s] me the strength.

I believe in a God who knows my trials and helps me through each step. I believe that if I depend on his strength, that I can succeed no matter what level of function I have or don't have.

For some respondents, religion (or spirituality, if respondents were not members of organized religious institutions) provided a sense of purpose and meaning in their present life on earth. It was also an important source of comfort in dealing with their anticipated future life following earthly death.

My faith in God really blossomed with my SCI. I know that I am right where He wants me to be.

I am crucified with Christ, therefore I will live. Everything in this life will eventually fade—so cling to what is eternal and everything will fall into place.

The promises for our future that are in the Bible help me be positive and excited for my future. (Psalm 37:29; Revelation 21:4).

I am a born-again Christian. Even after death I have hope.

A final theme mentioned by a few respondents reflected a sense of gratitude, praise, or thanksgiving for the blessings received. These were brief comments.

Every day is a blessing.

I am truly blessed with support and God.

In summarizing this section of the report it should be mentioned that the vast majority of respondents viewed religion and faith as functioning positively to promote resilience or the ability to cope. Only one respondent viewed religion as possibly a threat. This appears evident from the following comment:

I sometimes believe it is a test from a higher power or punishment for wrongful acts.

Physical health and functioning

Twenty-eight responses addressed issues related to health and functioning as affecting their ability to bounce back after a challenge. Specific health condition included issues related to SCI, such as bladder issues, impaired movement in the neck, numbness in the head and face, and spinal compression. Some respondents cited health conditions unrelated to SCI, such as cancer, heart conditions, and degenerative arthritis.

I have balance issues, given time I can pick myself up.

A theme emerged from within this category highlighting the impact of pain on resilience. Below are two examples:

My pain level is my main obstacle in doing just about anything. You cannot be proactive because I am constantly at the mercy of the pain.

The chronic pain makes it hard to bounce back. The pain drugs have had terrible side effects and have not worked.

Mood

Statements related to mood were present in 19 responses as influencing their ability to "bounce back" after SCI; as might be expected, these responses are fairly concordant with self-described level of happiness. Individuals who described themselves as happier generally either mentioned being happy with their lives and taking pleasure in facing adversity or in having a balance of positive and negative moods. The comments of these two individuals are representative:

I am happy to be alive every day.

In the seventeen years since my accident, I have never dealt with bouts of depression or anger. I take pleasure in defying the odds.

Several responses, though, were notable for a sense of despair.

I am in desperate search for a doctor supportive of assisted suicide.

The drugs used to treat my SCI have completely ruined my life. The anti-depressant used to control my nerve pain has caused severe depression that I never had before and I cannot escape from.

Comparisons

Comparisons (N=18) also emerged as a category from statements made by study participants. Within this category, two themes emerged: social comparisons and comparison to a

more general outcome. It is notable that none of the respondents who describe themselves as happy infrequently or not at all made comparison statements.

The social comparisons that were made were almost always downward comparisons, that is, respondents were comparing themselves to people they viewed as being "worse off" in some way than they themselves were. Responses in the Social Comparison theme indicated that with their physical limitations, they knew (or could visualize) other people who were "worse off" than they perceived themselves to be. For the most part these other people were not defined explicitly. Below are examples reflecting such comparisons.

Every time I've found myself at the lowest point, feeling that I can no longer deal with paralysis, I always manage to see someone worse off than me.

I know there are people worse off than I. So whenever I want to complain about things I want to do and can't, I try to remember that.

Only one respondent made what might be considered an upward comparison—a situation in which respondents viewed their lives unfavorably compared to other people with or without disabilities.

I met a "quad" who was physically much worse off than me but living his life just fine. I realized there was no reason why I could not do the same things and more.

A few respondents made more general comparisons, contrasting the current state of their lives with the way things could have been ("... things can always be worse"). Once again, these statements typically reflect that life and the current situation is better than it might be.

Resources

Finally, an eighth category emerged from responses in which a lack of access to resources or services was mentioned (N=10), including therapy, transportation and employment.

Most of the individuals who responded in this way reported that they were happy "some of the time"

Felt like I was bouncing back when I had regular PT. Insurance is no longer paying.

I know things could be worse. My main problem is having enough money to take care of my wife and monthly bills every month since they have cut my check down so low. It is hard for us.

Discussion

In this study, we sought to use responses to the question "What else should we know about your resilience or ability to 'bounce back' from a challenge?" to identify self-reported facilitators and barriers associated with adjustment and happiness following SCI. Eight categories were identified: Resilience, General Outlook on Life, Social Support and Social Relationships, Religion or Faith in a Higher Power, Physical Health and Functioning, Mood, Comparisons, and Resources. These categories encompassed eighteen overlapping themes which increased understanding of the factors that are related to resilience among adults with SCI living in the community. Consistent with previous research, ¹⁸ the majority of respondents described themselves as being happy "all or most of the time."

The category of resilience was the most frequently articulated in this study, likely because it was prompted by the format of the question which asked specifically about it.

Respondents, though, used the opportunity to claim it as a trait or skill that they possessed to varying degrees or to provide information about barriers or facilitators (including activities and strategies) to maintaining it. The concept of resilience was clearly one that resonated with participants and is relevant to better understanding the experiences of those individuals with SCI who have been successful in adjusting to their traumatic injury and going on with their lives. 19-20

The ability to be persistent, knowing how to face adversity, adaptability, personal growth, and finding meaning were all associated with "bouncing back" and are consistent with, and expand upon, existing research. In particular, they appear to overlap with the five factors of posttraumatic growth described by Tedeschi and Calhoun.²¹

The next category that was articulated was general outlook on life. In particular, most of the respondents reported a positive, optimistic approach to life concordant with their self-reported level of happiness. Responses in this categories include details about the role and importance of "attitude" that have been previously cited as impacting quality of life and adjustment among individuals with SCI.²²⁻²³ Respondents also identified actions or strategies they used to have positive outcomes. Those individuals who reported a negative outlook were likely to have described this as being a change from a previous approach to life.

Social support and social relationships were also well articulated as impacting resilience; a finding concordant with how physical disability and mobility impairment can have social consequences that can threaten a person's sense of connectedness to family and to the larger community. Respondents with SCI in this study were appreciative of the support they received from family and friends and described it as a positive factor in their integration back into community life and in promoting resilience. The importance of family and personal relationships has varied among studies, some stating they are unmet needs while others identify them as important to an individual's psychological and physical well-being. 24-26 This study supports the latter statement, with social relationships and social support articulated as key features of resilience.

The category of religion or faith in a higher power as a source of support was also clearly articulated by respondents and adds to the literature on adjustment to SCI. Little attention in the

SCI literature has been paid to whether or not (and how) people ask for and receive support from a higher power, including spiritual forces and spiritual beings such as God.²⁷ For most people, religion and church attendance are not the primary focus of their everyday lives.²⁸ However, the salience of religion (or faith in a higher power), as measured by its importance and centrality in people's lives, increases for people facing health-related crises.²⁹ The onset of SCI challenges one's sense of personal control and is likely to trigger religious or spiritual thoughts as a way of making sense out of one's life after SCI.³⁰⁻³²

The relationship between resilience and social comparisons is also not frequently discussed in rehabilitation research, though it is noted in research in the larger body of psychosocial research.³³ While this category of responses was one of the smaller seen, it appeared to be associated with better outcomes. Responses seem to suggest that a comparison with others who are viewed as less fortunate (either based on resources, level of impairment, or some other factor) is an adaptive response which motivates a sense of resilience.

Finally, the other categories of responses—including those of Physical Health and Functioning, Mood, and Resources—are consistent with and expand on previous research on satisfaction of life following spinal cord injury.³⁴⁻³⁵ This research shows that higher levels of distress and lower levels of life satisfaction are related to poorer health, higher levels of pain, and fewer resources.

Overall, results from this study highlight how many individuals with SCI view themselves as happy most of the time. This feeling appears to be connected with self-identification as being resilient, employing strategies to reframe one's experience, and having a sense of support from friends or a higher power.

Limitations

A primary limitation of this study is self-selection bias, that is, only individuals who decided to complete the open-ended question and participate in the larger survey were included. While the sample remains fairly large and diverse for a qualitative study, it is undoubtedly weighted to reflect the perspectives of individuals with SCI who had both the energy and motivation to participate.

Implications for future research

It is important that clinicians integrate into practice not only information that is based upon studies that demonstrate statistical relationships among and between variables but also information from the narrative qualitative approach that adds an understanding of the process of "successful adjustment." The approach of allowing the individual to reprocess and to identify new understandings and meaning for their life after such an injury, described by the participants here, is consistent with the current procedures of many clinicians. The use of such assessment findings to inform and influence well-directed plans for treatment may require a modification or expansion of one's underlying clinical framework. Continued research using the above approach to the adjustment process after SCI is needed and will allow the field to more fully identify, understand, and appreciate the positive aspects of the transformation.

Conclusions

The issue of resilience and ability to bounce back following SCI appears to be one that resonates with a significant number of individuals. Their responses reflected both supports as well as factors that make it harder to adjust.

References

- 1. Edhe DM. Application of positive psychology to rehabilitation psychology. In: Frank RG, Rosenthal M, Caplan B, eds. *Handbook of Rehabilitation Psychology*. Washington, DC: American Psychological Association; 2010:417-424.
- 2. Richards JS, Kewman DG, Richardson E, Kennedy P. Spinal cord injury. In: Frank RG, Rosenthal M, Caplan B, eds. *Handbook of Rehabilitation Psychology*. 2nd ed. Washington, DC: American Psychological Association; 2010:9-28.
- 3. North NT. The psychological effects of spinal cord injury: a review. *Spinal Cord*. 1999;37(10):671–679.
- 4. Heinemann AW, Doll MD, Armstrong KJ, Schnoll S, Yarkony GM. Substance use and receipt of treatment by persons with long-term spinal cord injuries. *Arch Phys Med Rehabil*. 1991;72(7):482–487.
- 5. Stanford RE, Soden R, Bartrop R, Mikk M, Taylor TKF. Spinal cord and related injuries after attempted suicide: psychiatric diagnosis and long-term follow-up. *Spinal Cord*. 2007;45(6):437-443.
- 6. Elliott TR. Defining our common ground to reach new horizons. *Rehabil Psychol*. 2002;47(2):131-143.

- 7. American Psychological Association. *FYI: Building Your Resilience*; 2015. http://www.apapracticecentral.org/outreach/building-resilience.aspx Accessed November 30, 2015.
- 8. Chevalier Z, Kennedy P, Sherlock O. Spinal cord injury, coping and psychological adjustment: a literature review. *Spinal Cord*. 2009;47:778-782.
- 9. Dean R, Kennedy P. Measuring appraisals following spinal cord injury: a preliminary psychometric analysis of the appraisals of disability. *Rehabil Psychol.* 2009;54(2):222-231.
- 10. Kennedy P, Evans M, Sandhu N. Psychological adjustment to spinal cord injury: the contributions of coping, hope and cognitive appraisals. *Psychol Health Med*. 2009;14(1):17-33.
- 11. Audu ML, Nataraj R, Gartman SJ, Triolo RJ. Posture shifting after spinal cord injury using functional neuromuscular stimulation--a computer simulation study. *J Biomech*. 2011;44(9):1639-1645.
- 12. Kennedy P, Lude P, Elfstrom ML, Smithson EF. Cognitive appraisals, coping and quality of life outcomes: a multi-centre study of spinal cord injury rehabilitation. *Spinal Cord*. 2010;48:762-769.

- 13. Diener E, Wirtz D, Tov W, Kim-Prieto C, Choi D, Oishi S, & Biswas-Diener R. New measures of well-being: flourishing and positive and negative feelings. *Social Indicators Research*. 2009;39:247-266.
- 14. Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction with Life Scale. *J Pers Assess*. 1985;49(1):71-75.
- 15. Dolan P, Peasgood T, White M. Do we really know what makes us happy? A review of the economic literature on the factors associated with subjective well-being. *Journal of Economic Psychology*. 2008;29(1):94-122.
- 16. Catanzaro M. Using qualitative analytic techniques. In: Woods NF, Catanzaro M, eds. *Nursing Research Theory and Practice*. St. Louis, MO: Mosby; 1988:437-456.
- 17. Morse J. Qualitative generalizability. *Qualitative Health Research*. 1999;9(1):5-6.
- 18. Bonanno GA, Kennedy P, Galatzer-Levy IR, Lude P, Elfström ML. Trajectories of resilience, depression, and anxiety following spinal cord injury. *Rehabil Psychol*. 2012;57(3):236-247.
- 19. White B, Driver S, Warren A-M. Considering resilience in the rehabilitation of people with traumatic disabilities. *Rehabil Psychol.* 2008;53(1):9-17.

- 20. White B, Driver SD, Warren AM. Resilience and indicators of adjustment during rehabilitation from a spinal cord injury. *Rehabil Psychol*. 2010;55(1):23-32.
- 21. Tedeschi RG, Calhoun LG. The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *J Trauma Stress*. 1996;9(3):455-471.
- 22. Siösteen A, Lundqvist C, Blomstrand C, Sullivan L, Sullivan M. Sexual ability, activity, attitudes and satisfaction as part of adjustment in spinal cord-injured subjects. *Paraplegia*. 1990;28(5):285-295.
- 23. Vissers M, van den Berg-Emons R, Sluis T, Bergen M, Stam H, Bussmann H. Barriers to and facilitators of everyday physical activity in persons with a spinal cord injury after discharge from the rehabilitation centre. *J Rehabil Med.* 2008;40(6):461-467.
- 24. Dijkers M, Abela NB, Gans BM, Gordon W. The aftermath of spinal cord injury. In: Stover SL, Delisa JA, Whiteneck GG, eds. *Spinal Cord Injury. Clinical Outcomes from the Model Systems*. Baltimore: Aspen: Baltimore; 1995:185–211.
- 25. Kennedy P, Rogers BA. Reported quality of life of people with spinal cord injuries: a longitudinal analysis of the first 6 months post-discharge. *Spinal Cord*. 2000;38:498–503.
- 26. McAweeney MJ, Forchheimer M, Tate DG. Identifying the unmet living needs of persons with spinal cord injury. *J Rehabil*. 1996;62:29–34.

- 27. Meade M, Jackson MN, Barrett K, Ellenbogen P. *Needs Assessment of Virginians with Spinal Cord Injury: Final Report: Findings and Recommendations*. Richmond, VA: Virginia Commonwealth University; 2006.
- 28. Gallop G. *Religion in America: The Gallup Report (Report No. 222)*. Princeton, NJ: Princeton Religion Center; 1984.
- 29. Pargament KI, Kennell J, Hathaway W, Grevengoed N, Newman J, Jones W. Religion and the problem-solving process: three styles of coping. *Journal for the Scientific Study of Religion*. 1988;27(1):90-104.
- 30. Bulman RJ, Wortman CB. Attributions of blame and coping in the "real world": severe accident victims react to their lot. *J Pers Soc Psychol*. 1977;35(5):351-363.
- 31. Duggan, CH. "God, if you're real, and you hear me, send me a sign": Dewey's story of living with a spinal cord injury. *Journal of Religion, Disability & Health*. 2000;4(1):57-79.
- 32. Keany KC, Glueckhauf RL. Disability and value change: an overview and reanalysis of acceptance of loss theory. *Rehabil Psychol*. 1993;38(3):199-210.
- 33. Todd JL, Worell J. Resilience in low-income, employed, African American women. *Psychology of Women Quarterly*. 2000;24(2):119-128.

- 34. Putzke JD, Richards JS, Hicken BL, DeVivo MJ. Predictors of life satisfaction: a spinal cord injury cohort study. *Arch Phys Med Rehabil*. 2002;83(4):555-561.
- 35. Putzke JD, Richards JS, Hicken BL, DeVivo MJ. Interference due to pain following spinal cord injury: important predictors and impact on quality of life. *Pain*. 2002;100(3):231-242.

Table 1. Demographic characteristics of sample (n=231)

Characteristic	n (%) or mean $\pm SD$ (range)			
Gender				
Male	182 (78.8)			
Female	45 (19.5)			
Missing	4 (1.7)			
Age (in years)	$53.82 \pm 13.59 (19-86)$			
Race				
White	187 (81)			
African American	21 (9.1)			
Multiracial	8 (3.5)			
Other	10 (4.3)			
Missing	5 (2.2)			
Education				
Not graduated from high school	9 (3.9)			
Completed high school / GED	47 (20.3)			
Some college or more	171 (74)			
Missing	4 (1.7)			
Marital status				
Single	57 (24.7)			
Married / partnered	122 (52.8)			
Separated / divorced	45 (19.5)			
Widowed	3 (1.3)			

Missing	4 (1.7)
Residence	
Urban	34 (14.7)
Suburban	83 (35.9)
Small town / rural	104 (45)
Missing	10 (4.3)
Military service	
Yes	103 (44.6)
No	125 (54.1)
Missing	3 (1.3)
Time since injury (in years)	$18.53 \pm 14.49 \ (0.25-66)$
Requires ventilator to breathe	3 (1.3)
Level of injury	
C1-C4	38 (16.5)
C5-C8	52 (22.5)
T1-T12	84 (36.4)
L1-S3	27 (11.7)
Don't know / not sure	22 (9.5)
Missing	8 (3.5)
Completeness of injury	
Feeling below level of injury	135 (58.4)
Movement below level of injury	126 (54.5)

Table 2. Self-reported happiness of participants (n = 231)

Happiness	n (%)	
All or most of the time	135 (58.4)	
Some of the time	71 (30.7)	
Very infrequently or not at all	25 (10.8)	
Missing	0 (0.0)	

Table 3. Classification of survey responses into categories and themes based on self-reported level of happiness

Categories and themes	Total	Happy all or	Нарру	Нарру
	N	most of the	some of	infrequently
		time	the time	or not at all
Resilience (overall)	99	53	36	10
Resilience claimed as a trait				
Facilitators and barriers				
Specific activities and				
strategies				
General outlook on life (overall)	82	62	14	6
Positive and optimistic				
Personal responsibility				
Other types of outlooks				
Social support and social relationships	49	35	11	3
Tangible assistance				
Motivational				
Reconnection with previous				
life				
Religion or faith in a higher power	36	29	7	0
Support in times of distress				
Meaning and purpose in				
one's life and after death				

Praise and thanksgiving				
Physical health and functioning	28	9	12	7
Specific impact of pain				
Other issues of health and				
effects				
Mood	19	7	7	5
Comparisons (overall)	18	11	7	0
Social comparisons				
General comparisons				
Resources	10	2	6	2
Total number of responses	341	208	100	33

Appendix C: Response Categories and Levels of Happiness

Category: Resilience (N=99)

Happy All or Most of the time

... Challenges with everyday life don't tend to stop me and I bounce back fine.

I bounced back through adaptive sports and my education/career. Without them I would be miserable. My recovery was about getting back to my "normal" before injury.

After my accident, I was able to bounce back to mostly a normal life.

Every challenge has a solution and unless you try those challenges you will never know what those challenges will bring.

Facing adversity and bouncing back is something I have done most of my life.

I am good at compensating. If I can't do something, I looked for a new way to do it.

I am very good at facing challenges.

Experiences prior to SCI were important after SCI.

I broke my back when I was eighteen I've learned to just push through the most difficult situations. I think it has made me a more resilient person.

I don't believe in the word "can't". It's either "I don't want to or I'll try.

I don't give up when I have a problem and I am persistent to overcome it.

I have been able to maintain my resilience when faced with challenges since my injury due to my personal growth in the past year and a half.

I just say 'I can, watch me prove you wrong.'

I'm rubber; you are glue whatever you say and bounces of(f) and comes back on me?

I'm very adaptable and have faced many abrupt changes in my life.

Purpose in life and sheer force of will can go a long way in overcoming major challenges -

One word that describes me, tenacious." I have also been called 'very intense.'

... it's a matter of trying and adjusting and trying some more.

I will bounce as high or as far as I am willing or able to go.

Never give up!

Adapt and overcome

My disability has made me very adept at dealing with adversity.

In high school, my senior year, I had to "bounce back" from a down junior year to get into a good college.

... I have never been fazed by the adversity I face and I take pleasure in defying the odds.

It is a constant battle, but after so any years you learn to bounce back quickly;

It is more difficult to "bounce back" emotionally, especially when trying to accomplish routine tasks that should take a minute or to but turn into 10-15 minutes or more.

Just 'keep on pushing' I find there are many more people worse off than myself.

just...never give up!

I always try to do things for myself before asking for help! I do get frustrated when I cannot do something but usually figure out a way to accomplish the task.

Mentally I am very strong and have been able to make the best out of bad situations through my entire life (prior and post SCI).

Most of my resilience is due to...my strong support system.

The chronic pain makes it hard to bounce back.

After my accident I received 1.5 months TX at a trauma hospital followed by 7 months at a comprehensive rehab facility. I think current, shorter rehabs result in discharge too soon not allowing decent level of adjustment and coping skills.

Think outside the box to accomplish activities etc. To stay independent.

I try to face every challenge. 90% I succeed.

I thrive on challenge, when I am told it can't be done is when I don't procrastinate and sometimes get something done. Being a residential builder and rough carpenter help build character, some would say I am hardcore.

I would rather do things myself and I will if I can, but I also will ask for help if I do need it.

The best ways I've found to bounce back is to help others and humor.

Distraction with activities- computer/family support

It is very hard when the govt restricts your monthly income so any set back is very devastating.

I seem to have good common sense have the ability to work things out I am good at rigging things up that work for me

I will try anything - I try even if I fail. Able to move on if things do not work out.

Strong will to live...

Very difficult but I try

Wish I were younger and better physically to "bounce back". Wish I didn't tire so easily.

Art with mouth

Finally, being back at work has helped me a lot.

Driving and working on cars, trucks, grass cutting, and active in VFW

Sometimes when things are in my favor like working on my project car...

I started feeding my horses/doing barn chores while still in a back brace. I was riding my horses <6 months after the accident and competing <1 year afterwards.

Apart from restructuring one's life after a SCI, one of the hardest readjustments has been, what to do with oneself, after retirement from work.

The ability to work after my accident ... was in my opinion, a life saver. I'm still trying to figure this one out (retirement). Understanding the limited options one has from a wheelchair, wasn't that much of an issue, when working. I took an early retirement (pending layoffs) because the work I enjoyed was going away and the contraction of the printing trade offered few other positive options.

I spend a lot more time around the house doing domestic chores (cooking and laundry), listening to an eclectic variety of music, working in the garage on bicycle / hand cycles and I'm planning to start (single hive) beekeeping again this Spring.

Bouncing back? There is no returning to the major things I did: the practice of [my profession], running along rural country roads, large scale vegetable gardening and extensive care of the grounds around my home. And I miss these things very much.

One would think I could still teach ...but even that is limited. The major teaching need is showing students what to do with patients ... (and this requires an ability of my trunk muscles to upright myself after leaning over - which I cannot do). Yes, occasionally, there are lectures I can give and articles I can get published, which gives some satisfaction, but it's not the extensive participation in [my profession] that I had before.

And, I do have a stand-up, stationary exerciser ... which provides an upper body workout of some intensity. I also have an arm operated tricycle that I can take out on the country roads, but getting on and off safely is a bit tricky, and is best used when my wife can 'spot me' while doing this (this has led to infrequent use of this). I also got my John Deere utility tractor modified so I can get up on it. But, again, help is needed to most safely get on/off of it- and in this case having a stronger/male person spotting me on this procedure is best, so he can also help in doing 'grounds care' cleanup of tree/bush trimmings. This need for a hired person has limited my participation in this grounds/tractor use.

But these things do not adequately replace the previous things I did.

I do try to keep up with what's happening in the world, by reading newspapers, magazines and following broadcast radio/television news- and I follow several TV series shows.

When I graduated

Happy Some of the Time

"Pick ya self up, dust ya self off, and start all over again.

Bullheadedly independent

Biggest challenge of my life, haven't been able to complete, yet.

Bounce back is very hard and very challenging. You have your good days and your bad days.

Bouncing back becomes more difficult in old age.

I try to never give up! After all these years it's hard to keep it up.

... I feel that my ability to recover from current and future medical issues is diminished due to spinal cord injury and age.

Even though the deck is stacked against me I have to keep getting up and moving forward because other people still depend on me...

Felt like I was bouncing back when I had regular PT. Insurance is no longer paying.

Older I get, harder it is, longer it takes

'press on' all you can do

Perseverance is the word I would use to describe myself

Try to be a problem solver

Get up = fall down + I

I bounced back at first, but it has become harder to fight all the time.

I don't let many things get in my way when there is something to be done.

Its hard, but necessary in life

I don't take "no" for an answer.

...It's always been two steps forward and five steps back. In that time I have pieced together a lot of successes. I always try to dust myself off

...I tell myself I'm the only one who has control of my life and can make it or break it, only me. I pull myself up by my bootstraps and move on.

I used to be able bounce back from any situation before my accident. Now I can't because of my spinal cord injury.

I've always been the type of person that if you tell me I can't do it, then I will find a way to do it. I'm proud that I live by myself after my spinal cord injury.

Try to do can about situation and sometimes think if I can keep trying results will be better.

I prefer not to argue

Patience

Much harder to bounce back now than it was 10 years ago or more.

My family and I have used many illustrations to reflect my resilience: Tigger, "bounce and re-bounce" etc... I know how to bounce.

Perseverance is the word I would use to describe myself.

You have to be flexible and open-minded. I had to learn entirely new skills, but now I have a better, higher-paying job than I did before my SCI. Some said I went back to school/work too quickly, but that was the best choice for me, I didn't want to become a 'professional patient.' Realizing I could still make a living and support from my family really helped me improve my outlook on the future.

I say to myself-this time will pass-when things become too difficult.

It's not always easy to bounce back. The move from Michigan ... was a plus because of the weather. The VA is beginning to help me with [medical issues and supplies] but appointments are hard to arrange with VA help and doctors.

Even though I had a good recovery following my initial injury and more recently had a good recovery following rotator cuff surgery last year; I feel that my ability to recover from current and future medical issues is diminished to spinal cord injury and age.

I am growing tired

...I don't think anyone bounces back after an SCI. You just become determined to get back as much as you can.

I'm going to school full time studying for a degree in CADD. I also play in pool leagues and enjoy them.

I would have answered strongly agree to every answer if it was not for a forced change in position at work in the last 6 months.

For about 90 days I have been practicing yoga...I cannot express enough how it has helped me regain some of my flexibility, balance, and overall happiness.

Happy Infrequently or Never

I bounce back well because I have always had to. I don't quit.

I have ups and downs when it comes to bouncing back. Sometimes I feel like giving up and other times I feel I can do anything.

My ability to bounce back has been affected by time and attempts to deal with a medical system that caress less and less for my welfare.

It is getting more and more difficult!

I can't bounce back so fast.

I never give up.

I no longer face problems/challenges head on. Instead I hide hoping these things will blow over or just go away.

I quit.

There is no such things as "bouncing back" from a SCI that leaves you in chronic constant pain for 10 years +.

Category: General Outlook (N=82)

Happy All or Most of the Time

The past is behind you. Stop looking back and focus on the present (what you can do and accomplish) future goals.

Be happy with what you have NOT what you didn't do or can't do.

I draw a dark line between 'acceptance' and 'adjustment' when it comes to my disability. My somewhat flippant answer to the question of how long it took me to adjust: 'I plan on being done with it a week from Thursday.' I have never adjusted well, but have accepted my situation (positively) through somewhat fatalistic/naturalistic language like 'Luck of the Draw,' 'go with the flow,' 'it is what it is,' and 'shit happens.' Also, my sense of curiosity -- 'I wonder where this will take me' -- has always been a prime motivator, and usually provides the resiliency to get through a situation or set-back.

Generally, I believe you can do anything you put your mind to.

i believe that i have to live to the best of my ability. if i can't do this then do that, i don't want to waste time feeling sorry for myself, cause there's only so much time left. i'm very fortunate to have a supportive family, because of my attitude, my extensive life experiences and advanced education many people seek my advice and counsel, this is very rewarding to me, also as i lived my life i was heavily engaged in it. i've done so many things i wanted to do do my bucket list is very short, as a result i don't lament about what i can't do but celebrate what i've done.

...Positive attitude, must move up or you will go down.

I put a strong emphasis on my healing because of...things to look forward to, work to do, people to help.

Attitude- eat right. Set goals

You either "get busy living or get busy doing".

I am self-care (Veteran) I do it all, I have to but doing for myself gives me a sort of high. I feel good after clearing, cutting grass, etc. I could never live some place where everything is done for me.

Keep in mind that the harder you work at having a better life the better your life will be.

Life is precious. Everyone has challenges and while paraplegia is visible there are many with tougher issues.

There is joy in overcoming challenges. Everyone can do it when it's easy.

...I try to take a realistic view of my options and try to choose the one that address the challenge and makes me happy. This particular philosophy has worked well for me before and after my SCI.

Attitude is key. Having a positive outlook on life helped me accept my abilities and their differences.

The restoring medicine in any temporary defeat is to face it. Zero in on the things I have instead of the things

...I have accepted my situation (positively) through somewhat fatalistic/naturalistic language...go with the flow....it is what it is...

I have a good attitude toward life and people who I know- I hardly ever complain- even though I am hurting I still don't complain. I enjoy most every aspect of my life to the fullest.

What I have learned from the situations that I have faced since being a T5 complete is follow the doctors instructions, and be completely upfront with them on all of your health conditions. And most of all pay attention to what your body is telling you. Because in the surgeries in which I have needed, the doctors always tell me that they appreciate me following their orders because it makes their jobs so much easier. Because I do care about my well-being.

Everyone has always told me I've had a positive attitude.

By focusing on others, it makes what happened to me seem less important.

Usually I try to be optimistic about my daily life with the help of my wife who takes care of me

Control only what you do control (yourself); influence what you can and the rest will settle.

Being able to address obstacles with a sense of humility, and having fun with the chair.

Drop back to remind myself what is most important. I think it's "being a good person". With that in mind, I think of what to do next with the challenge.

Each day is a blessing--the good, bad and challenging we may face. Tomorrow is new day, a new page of life.

...my parents raised me and instilled that I can do anything.

Life goes on whether you win or lose. Learn to accept change and life is a lot better to deal with.

I never cared much what people thought of me before the injury; I think this helped a lot after.

I always try to have a positive outlook. I try to fix things so as to have a positive outcome. I have faith in God. Love my life, sunshine, and green grass. I love my wife and family.

I approach life and problems associated with it one day at a time

Positive attitude goes a long ways.

I view the glass as being half full

I feel that you accept what life deals you...Learn to control future problems to the best of my ability.

I have a good attitude toward life...

One day at a time, eat right and sleep right

I have a positive outlook about life.

Positive attitude – [you] must move up or you will go down.

I like working on problems that make me think on how to get it working or be resolved. I also accept to the point when the problem is one that I or anyone else can't fixed.

If you don't do it, nobody else will.

Do what you enjoy.

While setbacks or problems related to my condition can be very frustrating, especially things like equipment breakdowns, I try not to get emotionally invested or bother by day-to-day hassles not related to my condition.

Always ask yourself: If not you, then who?

I look for the good in all things

Just continue to be yourself and keep working hard to get back on your feet.

...go backwards or forward. I'm not going backwards. Have to stay positive...

Live my life by two mantras: (1) It's not about where you been, but where you're going. (2) From Victor Frankel, "Man's Search for Meaning". "If you find mean(ing)/purpose in life, the "how will take care of itself ...teaching life lessons...my saving grace.

Purpose in life and sheer force of will can go a long way in overcoming major challenge.

It's up to me, go backwards or forward. I'm not going backwards, have to stay positive, but it is hard. But I'm alive and my 3 girls need me. I have a whole bucket of problems, so I just put a lid on it.

I just try to do the best I can. The quadriplegic thing wasn't my choice but I'm trying to make the best of it.

I believe I gained a better attitude about my disability from a few experiences during recovery. The moon info sessions during in-patient rehab were valuable. A positive therapy helped my attitude. I was in outpatient therapy for a few months, then at [another facility].

There is a solution to every problem. I am happy to be alive each day and share my smile or laugh with others. I am in gratitude.

...and I take one day at a time.

Positive outlook. Support[ive] family

What hinders us only makes us stronger.

Life= fall down + I

Just do the best that I can with what my ability is.

Work smarter, not harder. If you can't really use your body, use your mind.

Keeping a positive attitude and religion, you can't change the past, only the future

I think I've done great and though I don't have everything I need, I still am fortunate and live a very active life.

I am very analytical and don't let emotion drive my direction. I try to limit variables that may contribute to issues that arise. I only typically measure and change one variable at a time so I can see or understand the variables impact on my life.

Yes, when a person hits rock bottom in life; there is only one way to go. Never feel sorry for yourself, because all you have to do is open your eyes and note there are many people more deserving than yourself!

There is no returning to the major things I did...And I miss these things very much...But these things do not adequately replace the previous things I did.

Happy Some of the Time

Get up= fall down+1

Even though the deck is stacked against me I have to keep getting up and moving forward because other people still depend on me. Too bad jobs are not available for the handicapped. It would be nice to earn a living and support my family.

I always try to look on the bright side...

I am a positive person. ... but my injury have held me back...and that holds me back not only financially but emotionally.

I believe this trip is our only go-around in life...I've been tortured almost every day since my accident. I learned to turn pain into a positive. I live each day as full as I can...

Best I can in a wheelchair

I have my pity parties then I tell myself I'm the only one who has control of my life and can make it or break it, only me. I pull myself up by my bootstraps and move on. Everyone is caught up with their own lives and issues so with or without them I have to march on otherwise what's the point!

Bullheadedly independent

Be a kid, think how I'm going to get it done

...after my injury I have really felt as though my life has stopped.

I have been known for my ability to see the good in any situation. 'You always have a smile on your face' is not an uncommon statement to hear from others. However, this experience has been the most taxing to date in my life. I sometimes I feel I have 'met my match' as it were or even 'got the challenge I asked for'. So far I seem to be managing, but just barely.

I have done well in the past...I'm not at a high point...but I'll keep swinging...

I don't like to sit around worrying, I look for ways or ideas to try to make myself feel better. I like to walk and

exercise when I'm able to. I try not to dwell on negative things. I try to talk to people with the same symptoms I have to get some ideas on what I can do to make things better.

I try hard to remain optimistic in the face of a challenge.

Happy Infrequently or Never

I look at every day as an opportunity to be the best person I can for myself and, more importantly for the people around me.

I have worked through many issues over time. Sometimes it takes a lot both physical and mentally but I have managed. And I still have moments of 'why me' attitude.

When I broke my back and had surgery, I tried to be optimistic, but over the years of chronic pain, I have been worn down...

Confident life is better than death.

The drugs used to treat my SCI have completely ruined my life.

When you are asset everybody know you, when you become a liability nobody knows you. The longer you are a liability the worse it gets. Look at Michigan no-fault insurance. They trying to get off the hook and with all our money we paid into.

Category: Social Support and Social Relationships (N=49)

Happy All or Most of the Time

....I'm very fortunate to have a supportive family.

I put a strong emphasis on my healing because of my family...

- ... I do have many friends who help me as I live alone.
- ...Good support from friends that won't keep the chair from letting you do things.
- ...family.
- ...l am also blessed by a wonderful wife and family. I also appreciate my medical care and doctors.

Having a good wife and family is all important.

- ...I love my wife and family.
- ... I also benefited from being around other active disabled while biking, playing basketball, and various other activities.

I fear some sort of physical challenge in old age will make it too difficult for my family to deal with.

I have a lot of support from my family and friends...

Support[ive] family

- ... I have two children that have kept me motivated to not give up and live life as independently as possible.
- ...also, my family and support system is incredibly important to my ability to "bounce back".

I have my down days but thank God I am alive and have so many people that support me in anything I do.

In the 17 years since my accident I have never dealt with bouts of depression or anger because of my...family and friends.

...But I'm alive and my 3 girls need me.

Strong will to live because I am a very happy married man with a loving wife.

.. My children and teaching life lessons are my saving grace.

Most of my resilience is due to...my strong support system.

...My husband was a rock, and the care I got through [the health system] was great.

My...kids and friends.

...my husband; my family...

... And I spend fairly regular time with my wife, who watches over and tries to maintain my mental status.

My spouse is very supportive as are my children...

Stay engaged and help others. In the long run it's about service to others....

... I am a very happy married man with a loving wife.

Usually I try to be optimistic about my daily life with the help of my wife who takes care of me

The 1st two years were pretty rough but after that I was introduce to wheelchair sports from a group of my peers. It was my time to make a choice...

The single most important factor in being happy, productive, healthy is the support of family and friends...

Only when I encounter people who are not disabled, I do have a problem setting them to engage on a more personal level. Is it ignorance?

My family and friends keep me 'up.'

I was wounded in Vietnam a very troubled time in our country and own lives, what helped me most after being wounded I was sent to [an Army Hospital]. It was the doctors, nurses, and the people there that helped me most. They helped me come back home because in general the American peoples at home in America hold us Vietnam Veterans, won what did we do to them!

The support from family and friends to encourage.

When you think about family and how this challenge will help you and the around you, you overcome.

Happy Some of the Time

...I have to keep getting up and moving forward because other people still depend on me.

Good family and friends support are a huge help.

Having supportive family/friends, not having to do it alone, having someone there to encourage you to keep going...

Need help with social skills again

My wife takes really good care of me

...I try to talk to people with the same symptoms I have to get some ideas of what I can do to make things better.

Some days I feel more optimistic than others. I wouldn't say I'm a depressed person, but I can definitely get down on myself. I feel like my disability has made me not as social. I feel like I wish I could have what my friends have: a boyfriend/husband, kids and house, and just a happy little family. I'm successful on the academic and career front, but not the social front.

When I got hurt my wife was 7 I/2 months pregnant, then a year after my accident our house burnt to the ground, 9 years later my wife had an affair and subsequent divorce. I had a wonderful life and marriage (I thought) till then. The divorce by far has been the roughest thing to overcome and if it were not for my 2 daughters I would be in a bad place. I think I live my life by example for my girls

My wife's support helps. The love of my family helps.

I always try to look on the bright side, but if I can't, I have my family to support me.

The support my family and friends, would have no "drive to live and little future. They make me strive to be better and to go on a little further along life with a sure step.

Happy Infrequently or Never

...I look at every day as another opportunity to be the best person I can for myself and, more importantly, for the people around me.

Support and care from family.

Would like to help others, sick, elderly, etc. but unable

Category: Religion and Spirituality (N=36)

Happy All or Most of the Time

I put a strong emphasis on my healing because of my family and faith, things to look forward to, work to do, people to help.

Meditation and self-healing with Reiki.

A believer in a higher power.

Every day is a blessing...

God give me the "strength"

Only by the grace of God go I.

God helps me through prayer by His people and by myself. He guides me by His word also (i.e. the bible).

...I have faith in God.

I believe in a God that knows my trial and helps me through each step. I believe that if I depend on his strength that I can succeed no matter what level of function I have or don't have.

I believe my faith or Jesus Christ as my savior and His leading in my life gives me the strength to live my life.

My faith is my number one. I am truly blessed with support and God.

I have my down days but thank God I am alive and have so many people that support me in anything I do.

It all comes [down to] God. Always keep your faith.

... I get up each day, try to remember to thank God for all my blessing.

Most of my resilience is due to my faith...

My faith helped me tremendously

My faith in God, our Creator, helps me through my challenging moments.

My faith in God really blossomed with my SCI. I know I am right where He wants me to be. If my life were to be different He is the only one that could change it. He has also blessed me with a great sense of humor. Believe me with this lifestyle there really is humor. Hey, it's better than crying!

Self-worth is not from my abilities, my friends, or lack thereof - I am crucified with Christ therefore I will live. Everything in this life will eventually fade for everyone - so cling to what is eternal and everything seems to fall into place.

....I count my blessings daily...

The Lord Jesus Christis my strength, and in Him I put my trust.

The promises for our future that are in the Bible help me to be positive and excited for my future. (Psalm 37:29; Revelation 21:4)

Keeping a positive attitude and religion, you can't change the past, only the future

In the 17 years since my accident I have never dealt with bouts of depression or anger because of my faith, family and friends. I have never been fazed by the adversity I face and I take pleasure in defying the odds.

My faith

'Religion'

Stay engaged and help others. In the long run its about service to others and we must put God back into our principles. Without a moral compass we have no direction then anything goes and that's wrong.

Each day is a blessing-the good, bad and challenging we may face. Tomorrow is a new day; new page of life.

I was paralyzed from the neck down for 2.5 months. After I got up out of my wheelchair, I never wanted to sit in a wheelchair again! To this day I still refuse to sit in one! I credit my family, and my faith in god to all my recovery. I was I 9 when I was injured. Fresh out of the Marine Corps. Marines never give up. I never did, nor will I ever. God is awesome!

Happy Some of the Time

Amazing Grace.

Attempting to get through this ordeal with God's Grace.

You have your good days and your bad days but above all blessed to be where I am by God grace and mercy

I sometimes believe it is a test from a higher power (or punishment for wrongful acts.)

I am a born-again Christian. Even after death, I have hope.

In spite of my physical predicament I do have many blessings to count and I often count them to keep things in perspective. Also, the older I get the less time I have to be here in this world. Each day I live is one less day I have to serve in this prison sentence that is paralysis.

Faith and trust in God

Category: Physical (N=28)

Happy All or Most of the Time

Have faced about 3.5 years of fighting severe pressure ulcers and have been subject to a lot of bed rest.

Have medical challenges unrelated to SCI which impacts quality of life.

What I have learned from the situations that I have faced since being a t5 complete is follow the doctors' instructions, and be completely upfront with them on all of your health conditions. And most of all pay attention to what your body is telling you. Because in the surgeries in which I have needed, the doctors always tell me that they appreciate me following their orders because it makes their jobs so much easier. Because I do care about my well-being.

In the last 10 years I had a heart attack; 6 weeks later broke my neck. My daughter was diagnosed with

leukemia. U of M saved her life, and lost my mom two months ago. But I get up each day, try to remember to thank God for all my blessings!

I have balance issues, given time I can pick myself up.

Sometimes when things are in my favor like working on my project car, it's difficult getting up and down more than ever before. And bending for something you drop or can't pick up.

VA need to send my medications on time! I go several and a couple of times over 2 wk without getting them. It causes me to spasm uncontrollably. 3 times out of bed and out of my wheelchair when getting in and out! Causes bad withdrawals too. Your going to kill people this way! Or get a lawsuit!

The chronic pain makes it hard to bounce back. The pain drugs have had terrible side effects and have not worked.

When I fell in Florida, I was paralyzed. When they opened up my neck, my spine started pulsing...

Happy Some of the Time

-my largest challenge is my stamina. I have not been able to increase it by any substantial amount.
- ... I've been tortured almost every day since my accident. I learned to turn pain into positive.
- ...lt's hard to live with chronic pain; it takes a toll on me physically and mentally.

Just chronic debilitating pain

For about 90 days I have been practicing yoga...I cannot express enough how it has helped me regain some of my flexibility, balance, and overall happiness.

When I broke my neck, I was told I wouldn't walk again for 6 months to two years and I am able to walk after 6 months.

When it comes to my health I am very in charge of it. As soon as I have a problem I get it checked out.

I have had 12 separate surgeries in 15 years. It's always been two steps forward and five steps back

I have persistent pain at the level of my injury (T4). If I could manage that my outlook would be better.

Since my fall 3.5 years ago, most all feelings have come back and just wish I could get help to gain strength back, and lose weight I have gained but need help so I can walk again. I am sure someone could help with therapy.

Life has not been easy for me since after the accident. It has been pains all over my body and three surgeries on the two shoulders and neck. I really need employment to assist in family expenses and my personal pocket money too.

...since my neck incident I have been discovered to have liver cancer.

Happy Infrequently or Never

When I broke my back and had surgery, I tried to be optimistic, but over the years of chronic pain, I have

been worn down...

Nerve pain drives me crazy 70% of the time.

Due to a severe ulcer that I am going to Ann Arbor VA this month for surgery that was caused by a bad shower chair that took I year to replace I hope to become more active and get a life again. Right now I spend 20 hrs a day in bed.

I still would like to walk again so that would be a challenge that I would be looking forward to.

I have tried to be optimistic but over the years of chronic pain I have been worn down.

...the antidepressant used to control my nerve pain has caused severe depression... that I cannot escape from

There is "no such thing" as "bouncing back" from a SCI that leaves you in chronic constant pain for 10 years.

Category: Mood (N=19)

Happy All or Most of the Time

I cried every day for a few months....

I am happy to be alive each day and...

At this point, I'm happy for the experiences and memories but ready to wrap things up - not suicide, just content for what has been-

... I do get frustrated when I can't do something but...

I fear some sort of physical challenge in old age will make it too difficult for my family to deal with.

I experienced PTS disorder. It comes and goes. Have difficulty in moving forward- no motivation- no drive. Fear and anxiety. Drs. don't necessarily care to treat me for this. They expect me to just get over it!

In the 17 years since my accident I have never dealt with bouts of depression or anger...I take pleasure in defying the odds...

Happy Some of the Time

Every time I've found myself at my lowest point, feeling like I can no longer deal with paralysis, I always manage to see someone much worse off than I am. In spite of my physical predicament I do have many blessings to count and I often count them to keep things in perspective. Also, the older I get the less time I have to be here in this world. Each day I live is one less day I have to serve in this prison sentence that is paralysis.

...practicing yoga...l cannot express enough how it has helped me regain....overall happiness.

I get frustrated when I can't do things I used to do before my spinal cord injury. My moods are up and down

constantly.

Some days I feel more optimistic than others. I wouldn't say I'm a depressed person, but I can definitely get down on myself. I feel like my disability has made me not as social. I feel like I wish I could have what my friends have: a boyfriend/husband, kids and house, and just a happy little family. I'm successful on the academic and career front, but not the social front.

...I'm not at a high point, but...

.... I've recently quit smoking because I am not happy with how little I can contribute to the world around me however I'm not finished living and there's so much I still want to do in life I just feel stuck:

I have my pity parties...

Happy Infrequently or Never

My ability to bounce back has been affected by time and attempts to deal with a medical system that cares less and less for my welfare. I am in desperate search for a doctor supportive of assisted death. I've considered starting a crowd sourcing project for the purpose, and have no doubt it would be funded overnight- in the same world where I can't get a ride to the doctor or grocery store.

The drugs used to treat my SCI have completely ruined my life. The anti-depressant used to control my nerve pain has caused severe depression that I never had before and I cannot escape from.

I can't seem to overcome the frustration of not being able to do what I once could, anger is an issue. What I most liked to do I can't do any longer. I should be happy with what I have but I'm not.

Too depressed

Look at Michigan no-fault insurance. They trying to get off the hook and with all our money we paid into. They have plenty of money, but will not open the MCCA books. By the time they have to, the books will be fake

Category: Comparisons (N=18)

Happy All or Most of the Time

...someone else always has it worse than you.

I think I 'bounced back' faster than most after my injury. I cried every day for a few months, then I met at 'quad' who was physically much worse off than me, but living his life just fine with a good job, still had fast cars, women attracted to him. It was at that point I realized there was no reason I could not do the same things and more.

Everyone has problems, many are worse than me...

I find there are many more people worse off than myself.

I always take into consideration that there are always people worse off than me.

I know there are people worse off than I. So whenever I want to complain about things I want to do and can't I try to remember that.

I realize that there is someone always worse off than me.

More people than myself (are) worse physically than me.

The 1st two years were pretty rough but after that I was introduced to wheelchair sports from a group of my peers. Once I saw how they were dealing with SCI etc... it was my time to make a choice. Sleep, drink, and drug my life away. -Or- move on life and be thankful for/with what I have. I count my blessings daily:)

When I fell in Fla. I was paralyzed, when they opened up my neck, my spine started pulsing. I could have been paralyzed for life. Things can always be worse.

Realizing that it's not the end of the world and could always be worse.

Every time I've found myself at my lowest point, feeling like I can no longer deal with paralysis, I always manage to see someone much worse off than I am. In spite of my physical predicament I do have many blessings to count and I often count them to keep things in perspective. Also, the older I get the less time I have to be here in this world. Each day I live is one less day I have to serve in this prison sentence that is paralysis.

Happy Some of the time

I feel like I wish I could have what my friends have: a boyfriend/husband, kids and house, and just a happy little family. I'm successful on the academic and career front, but not the social front.

You learn to accept your condition knowing that it could be worse.

Knowing things could always be worse.

We all have a cross to bear, others have it better, many, have it much worse.

I know things could be worse. My main problem is having enough money to take care of my wife and monthly bills every month since they have cut my check down so low. It is hard for us.

You learn to accept your new condition, knowing it could be worse.

Category: Resources (N=10)

Happy All or most of the time

It is very hard when the govt restricts your monthly income so any set back is very devastating.

I would like my vehicle fixed. I need \$150 for a new electric fuel pump. Another \$80 for used tires. Has lift and driving controls. I feel trapped at home.

Happy Some of the time

I know things could be worse. My main problem is having enough money to take care of my wife and monthly bills every month since they have cut my check down so low. It is hard for us.

Felt like I was bouncing back when I had regular PT. Insurance is no longer paying.

Even though the deck is stacked against me I have to keep getting up and moving forward because other people still depend on me. Too bad jobs are not available for the handicapped. It would be nice to earn a living and support my family.

Since my fall 3.5 years ago, most all feelings have come back and just wish I could get help to gain strength back, and lose weight I have gained but need help so I can walk again. I am sure someone could help with therapy.

Life has not been easy for me since after the accident. It has been pains all over my body and three surgeries on the two shoulders and neck. I really need employment to assist in family expenses and my personal pocket money too.

If insurance would have covered more therapy, I think I would have walked again.

Happy Infrequently or never

Lack of transportation, employment

... I've considered starting a crowd sourcing project for the purpose, and have no doubt it would be funded overnight- in the same world where I can't get a ride to the doctor or grocery store.